

Testimony of Shelagh McClure
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H.B. No. 5030 AN ACT MAKING ADJUSTMENTS TO STATE EXPENDITURES FOR THE FISCAL YEAR ENDING JUNE 30, 2015.

Thank you to Sen. Bye, Rep. Walker and Members of the Appropriations Committee for the opportunity to submit testimony on H.B. 5030.

Today's system for adults with intellectual disabilities is one that provides residential assistance only if it is an emergency, defined as incapacitated or no parents, or where the individual with an intellectual disability (ID) is so ill or has some other condition that it is impossible for the individual to stay in his or her current home. And even that system is inadequate, unable to place all individuals who face emergencies, because there are insufficient funds. I implore you to ask DDS about the horrendous situations some families have faced that did not qualify as an emergency. It would make you weep.

And who else is getting lost when we have such a system, that doesn't even serve the most desperate? All of the young people like my son, who is 23 and has Down Syndrome, who we have prepared for a full life, as fully- included members of their community, only to be confronted with the reality that their chance for assistance to live in the community is years, if not decades, away.

DDS says this is a time of transition; that too many individuals currently receive residential supports that cost hundreds of thousands of dollars annually, and that is too expensive. As the parent of a 23 year old, I readily acknowledge that the current system is too expensive, but I'm not looking for an institutional or group home setting for my son, nor are many parents-but we are still looking to DDS to provide leadership; to provide a system in which residential placements are available and suited to our family member's particular needs--and that the period of time that my son and others must wait for those placements should not depend on my health or his health, but rather should be available at the time that other young adults naturally transition from living at home.

DDS is currently going through a process to reinvent the system, which is appropriate. But in the meantime, they have ceased planning and serving the vast majority of individuals seeking residential services, with no plan for when such services will be restored. They currently have no funds available to place any additional individuals, and the budget adjustments outlined in H.B. 5030 provide no funds for additional placements.

I see two jobs ahead that require this committee's attention and support: (1) make sure that there are adequate funds in the budget adjustments for, at a minimum, providing residential placements for individuals currently on the DDS emergency list; and (2) institute a system that provides a sure and orderly process for adults with ID to receive residential supports. Do not permit DDS to maintain the current paralysis. While the first task --emergency placements-- may seem more urgent, I believe they are both urgent. The number of individuals waiting for residential services grows daily, and the system cannot be paralyzed indefinitely-- or it will create additional problems of resources and priorities.

Thank you again for the opportunity to present this testimony.